SPINA BIFIDA ASSOCIATION

Transition Practices & Programs

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Disclosures

No conflicts of interest to report

Child Neurology Foundation

Transition of Care Program

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Child Neurology FOUNDATION
Creating a Community of Support

CNF Transition of Care Program

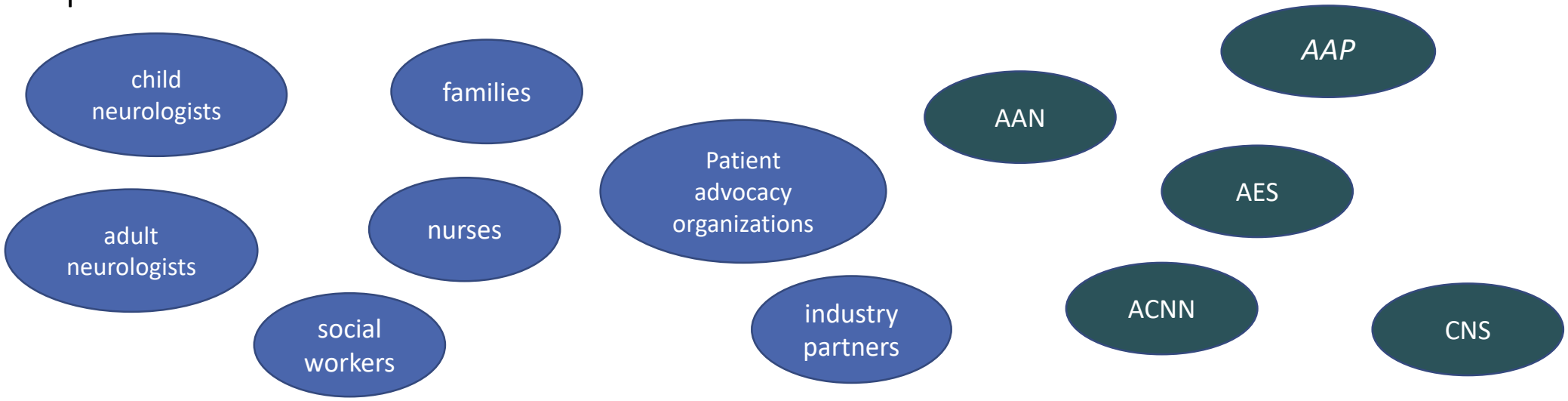
Our largest, most comprehensive program

Helping to support youth, families, and child neurology teams in the medical transition from pediatric to adult health care systems.

Transition of Care Program
Child Neurology Foundation
TRANSITIONS PROJECT ADVISORY COMMITTEE (TPAC)

CNF transitions initiatives are developed with Transitions Project Advisory Committee (TPAC) -- established to guide transitions initiatives with focus on the broader neurology community.

TPAC composition reflects the diverse and collaborative spirit of our partners.



but wait…

funny story…

Clinical Guidance (Peds)

- 2011 AAFP/AAP/ACP clinical report: *Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home*

"Primary care physicians, nurse practitioners, and physician assistants, as well as **medical subspecialists**, are encouraged to adopt these materials and make this process **specific to their settings and populations**."

Consensus Statement (Neuro)

- 2014: CNF assembled a multidisciplinary group to look at transitions with a child neurology lens
- 2016: Endorsed by AAN/AAP/AES/CNS consensus statement: *The Neurologist's Role in Supporting Transition to Adult Health Care*

- Identified **8 Common Principles** for the neurology team to adapt and employ; leading to and supporting a successful medical transition of youth/young adult with neurologic conditions.

ACP Pediatric to Adult Care Transitions Initiative

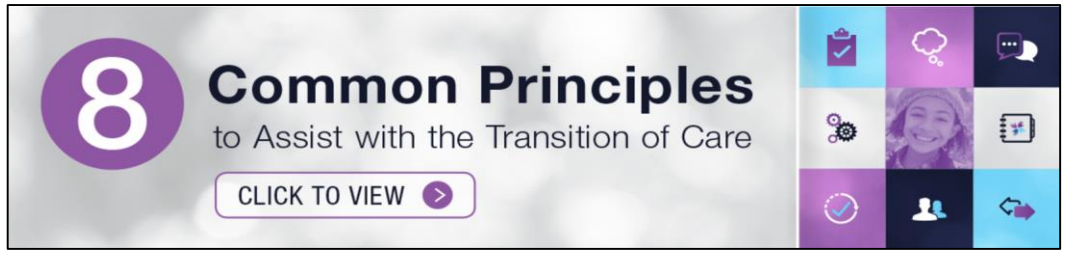
- 2016: American College of Physicians national initiative to address gaps in care related to transitions, across disciplines
- Each discipline was asked to create a toolkit "package" customized to the transition needs of their specialty
- AAN was invited to represent neurology but did not have a formal transition effort in place
- CNF TPAC was asked represent the neurology community in the initiative

- TPAC developed and finalized package of tools in May 2017:
  - Transitions Policy
  - Transitions Checklist
  - Self-Care Assessment (Youth/Young Adult)
  - Self-Care Assessment (Parents/Caregivers)
  - Transitions Package Cover Sheet
    - Transfer Letter Sample
    - Plan of Care
    - Medical Summary: Transitioning Patient

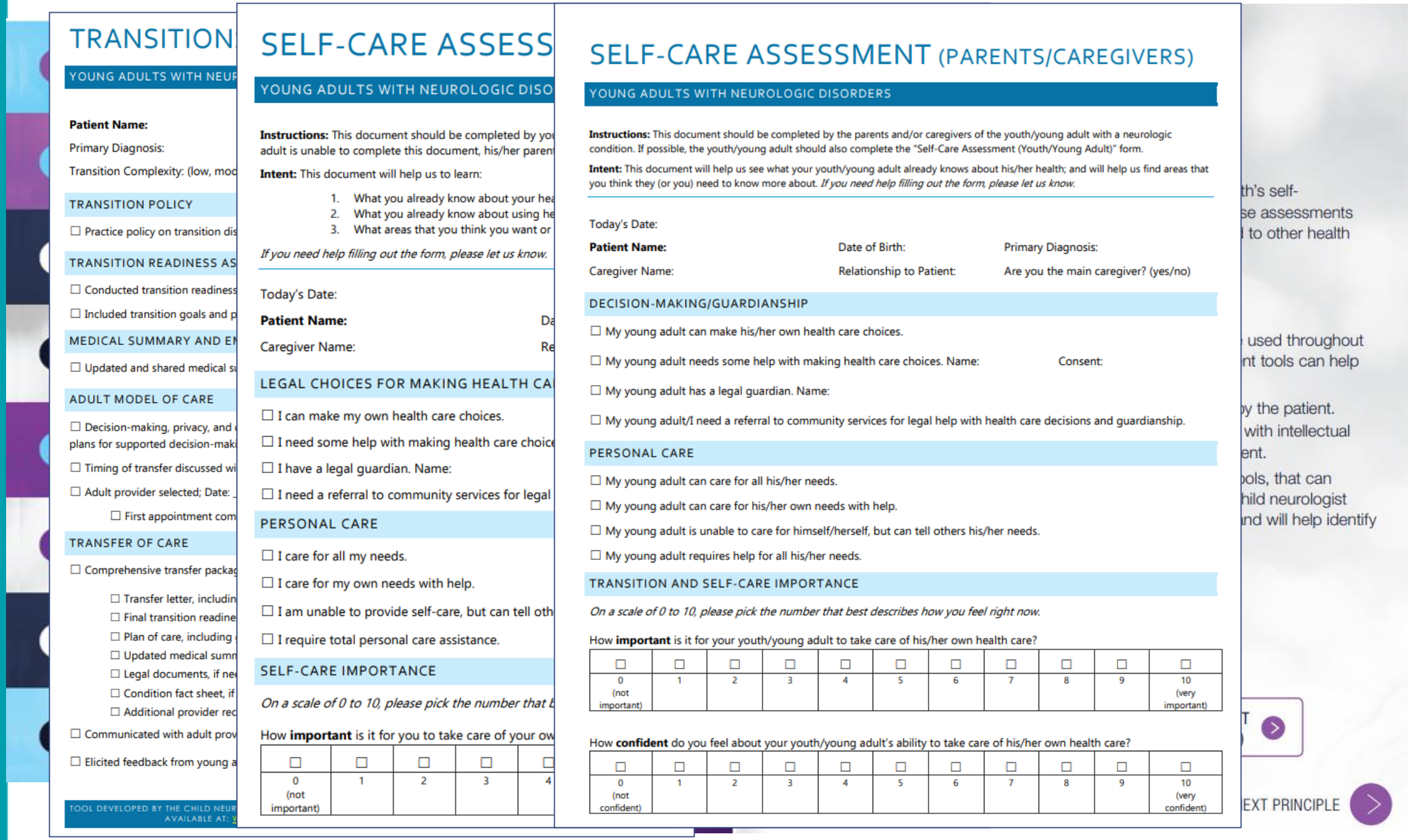
Dissemination

We have 8 Common Principles… we have new Transitions Tools… Now what?

CNF's online Interactive Graphic matches each of the 8 Common Principles to applicable tools. Download and use in practice.



childneurologyfoundation.org/transitions



TRANSITION

YOUNG ADULTS WITH NEUR

Patient Name:

Primary Diagnosis:

Transition Complexity: (low, moc

TRANSITION POLICY

☐ Practice policy on transition dis

TRANSITION READINESS AS

☐ Conducted transition readiness

☐ Included transition goals and p

MEDICAL SUMMARY AND EM

☐ Updated and shared medical su

ADULT MODEL OF CARE

☐ Decision-making, privacy, and
plans for supported decision-maki

☐ Timing of transfer discussed wi

☐ Adult provider selected; Date:

☐ First appointment com

TRANSFER OF CARE

☐ Comprehensive transfer packag

☐ Transfer letter, includin
☐ Final transition readine
☐ Plan of care, including
☐ Updated medical summ
☐ Legal documents, if ne
☐ Condition fact sheet, if
☐ Additional provider rec

☐ Communicated with adult prov

☐ Elicited feedback from young a

TOOL DEVELOPED BY THE CHILD NEUR
AVAILABLE AT:

SELF-CARE ASSESS

YOUNG ADULTS WITH NEUROLOGIC DISO

Instructions: This document should be completed by yo
adult is unable to complete this document, his/her paren

Intent: This document will help us to learn:

1. What you already know about your hea
2. What you already know about using he
3. What areas that you think you want or

If you need help filling out the form, please let us know.

Today's Date:

Patient Name: Da

Caregiver Name: Re

LEGAL CHOICES FOR MAKING HEALTH CA

☐ I can make my own health care choices.

☐ I need some help with making health care choice

☐ I have a legal guardian. Name:

☐ I need a referral to community services for legal

PERSONAL CARE

☐ I care for all my needs.

☐ I care for my own needs with help.

☐ I am unable to provide self-care, but can tell oth

☐ I require total personal care assistance.

SELF-CARE IMPORTANCE

On a scale of 0 to 10, please pick the number that b

How **important** is it for you to take care of your ow

☐	☐	☐	☐	☐
0 (not important)	1	2	3	4

SELF-CARE ASSESSMENT (PARENTS/CAREGIVERS)

YOUNG ADULTS WITH NEUROLOGIC DISORDERS

Instructions: This document should be completed by the parents and/or caregivers of the youth/young adult with a neurologic condition. If possible, the youth/young adult should also complete the "Self-Care Assessment (Youth/Young Adult)" form.

Intent: This document will help us see what your youth/young adult already knows about his/her health; and will help us find areas that you think they (or you) need to know more about. *If you need help filling out the form, please let us know.*

Today's Date:

Patient Name: Date of Birth: Primary Diagnosis:

Caregiver Name: Relationship to Patient: Are you the main caregiver? (yes/no)

DECISION-MAKING/GUARDIANSHIP

☐ My young adult can make his/her own health care choices.

☐ My young adult needs some help with making health care choices. Name: Consent:

☐ My young adult has a legal guardian. Name:

☐ My young adult/I need a referral to community services for legal help with health care decisions and guardianship.

PERSONAL CARE

☐ My young adult can care for all his/her needs.

☐ My young adult can care for his/her own needs with help.

☐ My young adult is unable to care for himself/herself, but can tell others his/her needs.

☐ My young adult requires help for all his/her needs.

TRANSITION AND SELF-CARE IMPORTANCE

On a scale of 0 to 10, please pick the number that best describes how you feel right now.

How **important** is it for your youth/young adult to take care of his/her own health care?

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
0 (not important)	1	2	3	4	5	6	7	8	9	10 (very important)

How **confident** do you feel about your youth/young adult's ability to take care of his/her own health care?

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
0 (not confident)	1	2	3	4	5	6	7	8	9	10 (very confident)

MEDIC

YOUNG ADUL

Instructions: caregivers.

Intent: This d himself/herse

Patient Info

Patient Name:

Date Form First

Date/s Form Re

Form Complete

Principal Tra

Name:

Address:

Work number:

Email:

Transitionin

Name:

DOB:

Address:

Cell #:

Email:

Parent (Caregiv

Address:

Cell #:

Email:

Health Insuranc

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Health Care Pr

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Specialty Provider

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Behavioral Health

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Equipment, Appliances, and Assistive Technology (note all that apply)

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Communication

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Prima *(Printe*

Prima *(Signa*

Phone Number | **Date**

Neurology Provider Name *(Printed)*

Neurology Provider Name

Prior Medications for Complex Medication Histories (eg, epilepsy)

Medication	Duration	Reason Discontinued & Comments

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MEDICAL SUMMARY TRANSITIONING PATIENT

2017 CNF Transition of Care Video Series

The series underscores the importance of partnership, communication, and a defined process to ensure successful transition of care.

- Journeys of 2 patients and families as they approach transition.
- Perspectives and experiences of national transitions experts–child and adult providers who care for individuals with neurologic conditions–through in-depth interviews.

Patient and Caregiver perspective: Katie, a 23-year-old woman who lives with cerebral palsy, epilepsy, and other health issues, and her parents discuss the transition process.

Provider discussion:
"Why is transition such an important time for adolescents?"
"What concerns do families typically express?"
"What advice do you give to parents?"
"What types of support does the CNF offer for transition?"

What we've heard…

- Patients, parents/caregivers unwilling to transition
- Adult providers lack experience with my child's condition
- I transition them… and they come back!
- There isn't an adult provider near where I live
- Difference in pediatric vs adult culture
- Aging out, but youth is unready/unwilling to take adult responsibility
- Sometimes, an adult patient just "shows up" in my waiting room and I know nothing about them
- Payment/Reimbursement in adult neurology
- Patient seen by multiple providers without a medical home (fragmentation of care)
- No time to discuss transition, I have to address the "important things"
- What will happen to my "adult child" after my husband and I pass away?

What's Next?

Based on

8 Common Principles

2017 Data from Providers:

Survey

- Fielded to a sample of AAN members (n=1000; 500 child neurologists and 500 adult neurologists) on transition of care

Focus Groups

- Conducted at the AAN conference; 2 groups of child neurologists and 2 groups of adult neurologists assembled

Get transition in the literature! Findings now being translated by TPAC members into an article with a quantitative focus; will be submitted in later 2019

What's Next?

Based on

8 Common Principles

Updates: Toolkit revamp

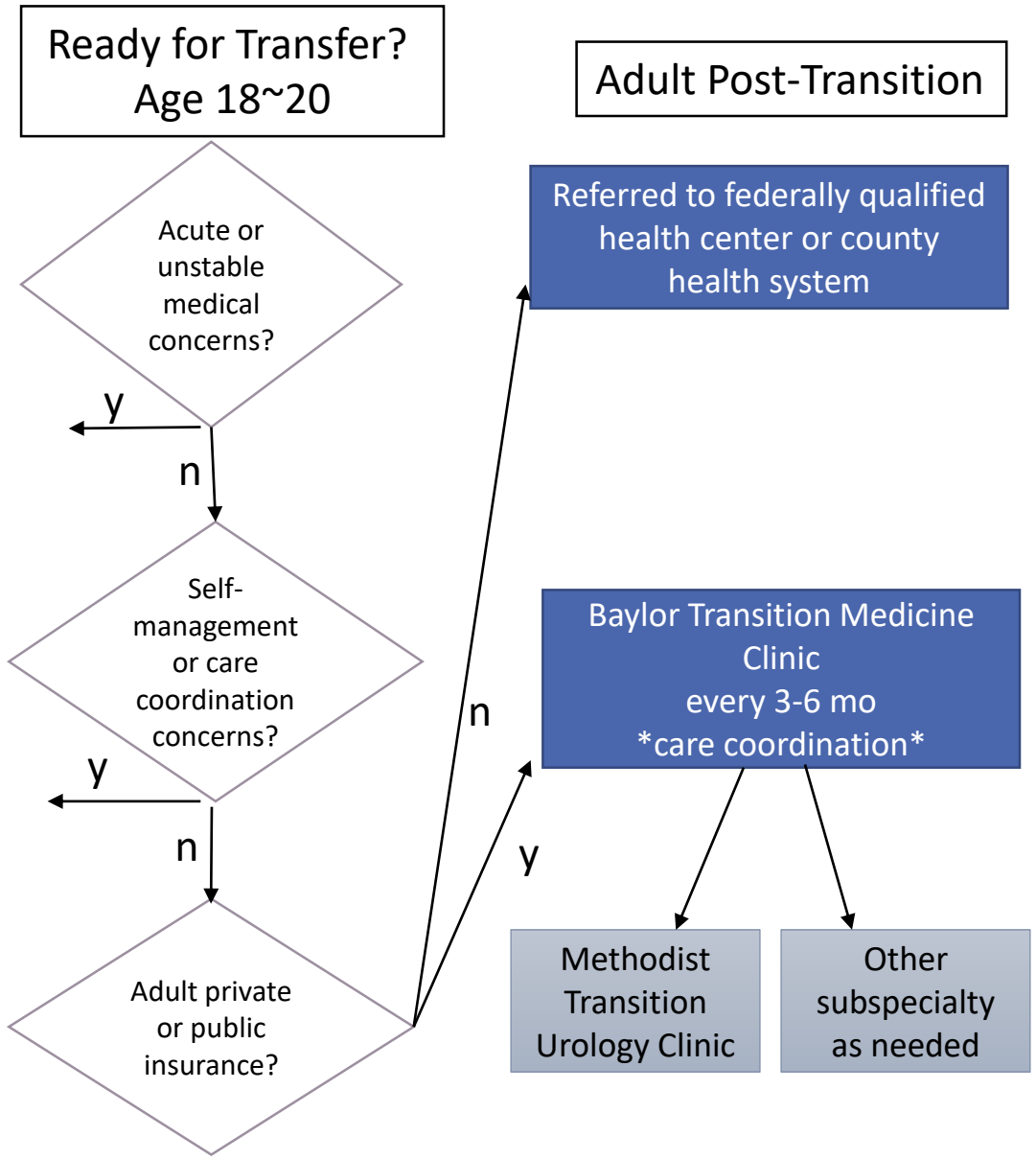
- Minor wording updates
- Easier to populate/print
- Easier to share via EHR
- Better overall tool for providers and caregivers
- Spanish translation

Concerted engagement with adult neurology community

- Best practices for both pediatric and adult settings
- Integrated education
- More networking

Transition to Adult Care for Texas Children's Hospital Spina Bifida Clinic

	Age <14	Transition Prep Age 14-18~20
Transition Care		TCH SB Transition clinic every 3-6 mo *care coordination*
Subspecialty Care	TCH SB Multidisciplinary Clinic *care coordination*	Annual TCH SB Multidisciplinary Clinic until age 18
Primary Care	Community PCP Annual/Acute visits	Community PCP Annual/Acute visits



Clinic Providers Available

TCH Multidisciplinary Clinic: developmental pediatrics, care coordinators, neurosurgery, PM&R, PT/OT, nutrition, urology, orthotics, orthopedics, child life

TCH Transition Medicine: Med-Peds, Urology nurse, Social Worker

Baylor Transition Medicine: Med-Peds, Social Worker, Nurse Coordinator, Medicaid Service Coordinator, Ob/gyn

TCH/BCM Transition Framework

GOT TRANSITION

6 Core Elements

- ✓**Transition Policy**
- ✓**Transition Tracking**
- ✓**Transition Readiness Assessment and Intervention**
- ✓**Transition Planning**
- ✓**Transfer of Care**
- ✓**Transfer Completion**

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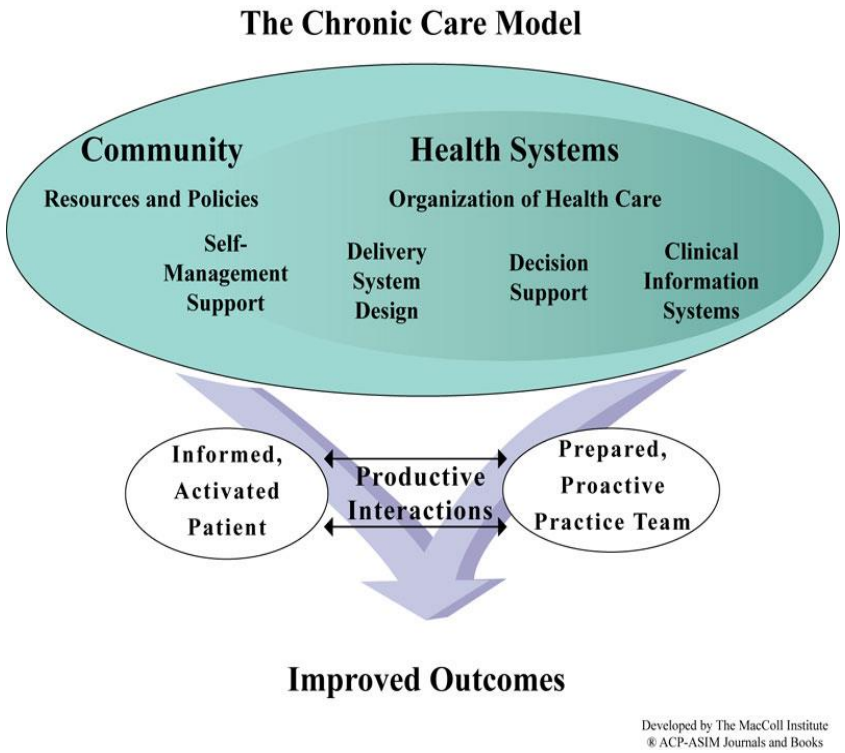

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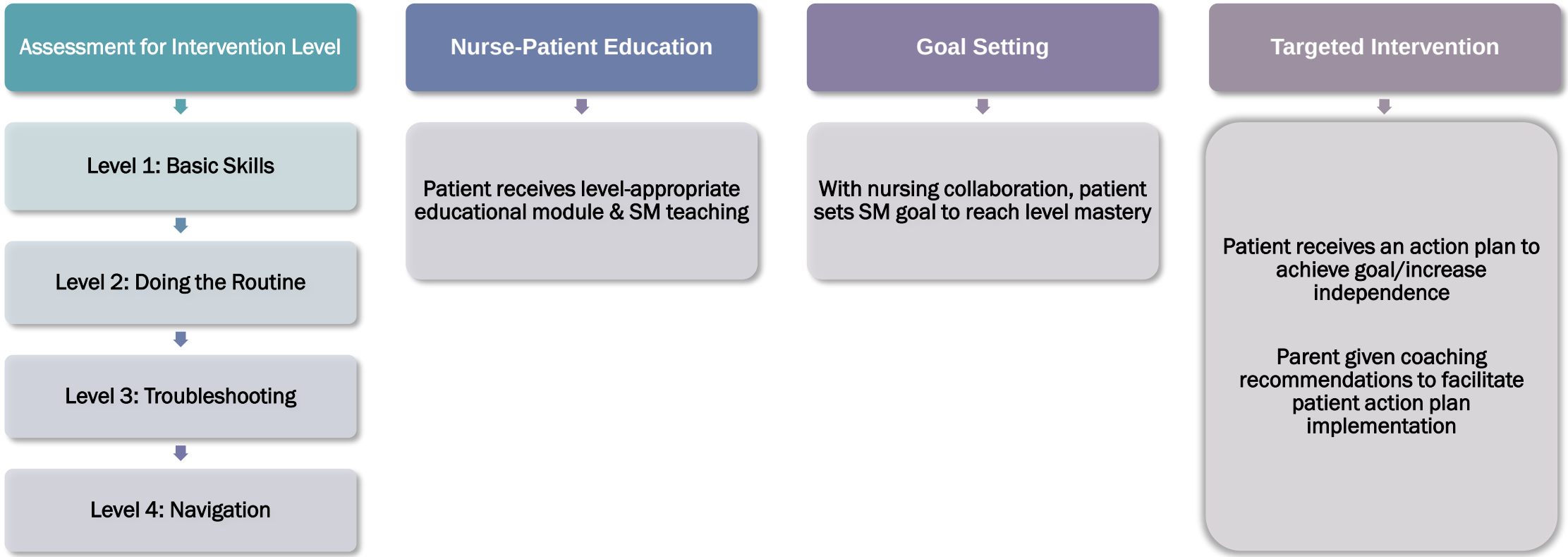
TCH Transition SB Readiness Clinic

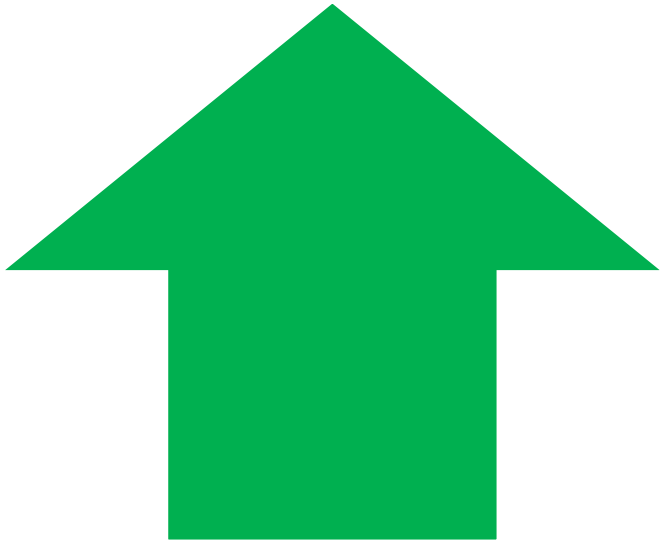
SB-specific Self-Management Goal-Setting



Why our model works in Houston

- Large population of patients with SB in the Houston area
- Pediatric and adult care partnerships in a single medical center
- Provider who can see patients in the pediatric and adult setting
- Designated nurse care coordinator and social worker for transition
- Program based on identified patient and family needs
- Goal-setting strategy gives a structured process that is adaptable to many functional levels

Cost/Benefits



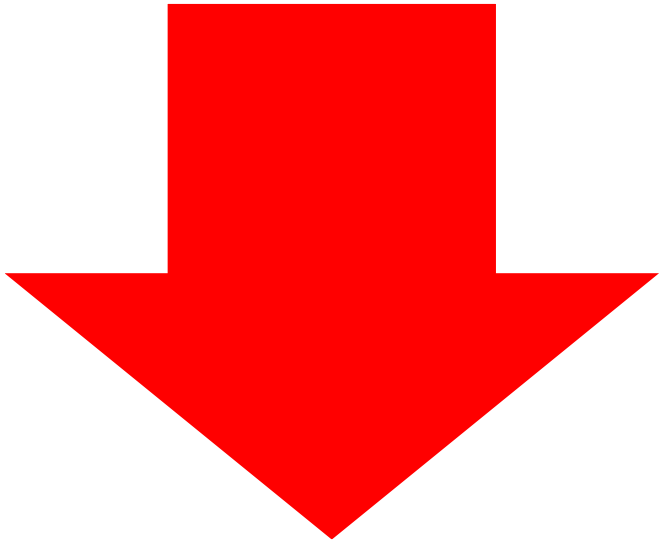
Benefits

*Development of a strong provider/patient relationship that is stable during the many changes of the transition process

*Chronic management and follow-up similar to other chronic conditions such as Diabetes or Cystic Fibrosis

*Time for self-management goal-setting and education

*Care coordination



Cost

*Staffing

*Visits are long ~ 1-2 hours

*Care coordination

*Insurance reimbursement

*Adult medical home clinic relies on funding from the pediatric hospital

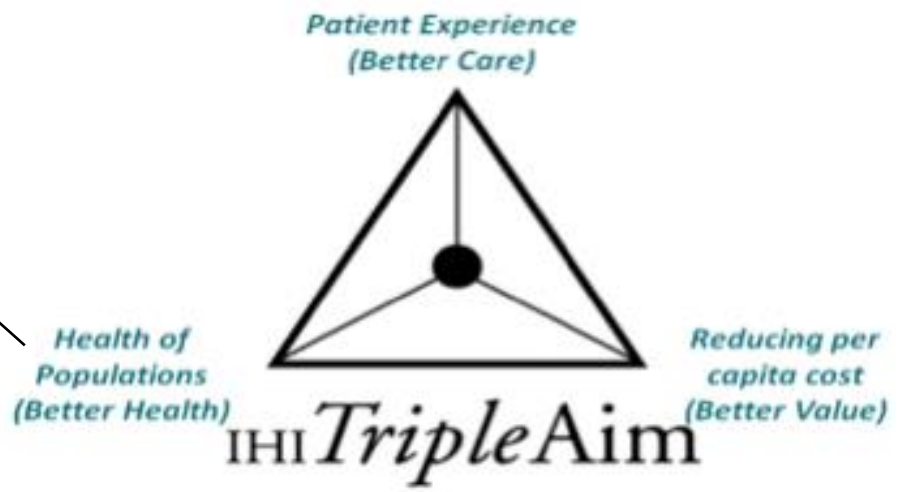
Measures of Success

Got Transition
Post-Transition Survey

Health Outcomes
- NSBR (pedi side)

Self-Management
- AMIS
- TRAQ-SB (in future)

Quality of Life
- QUALAS-T

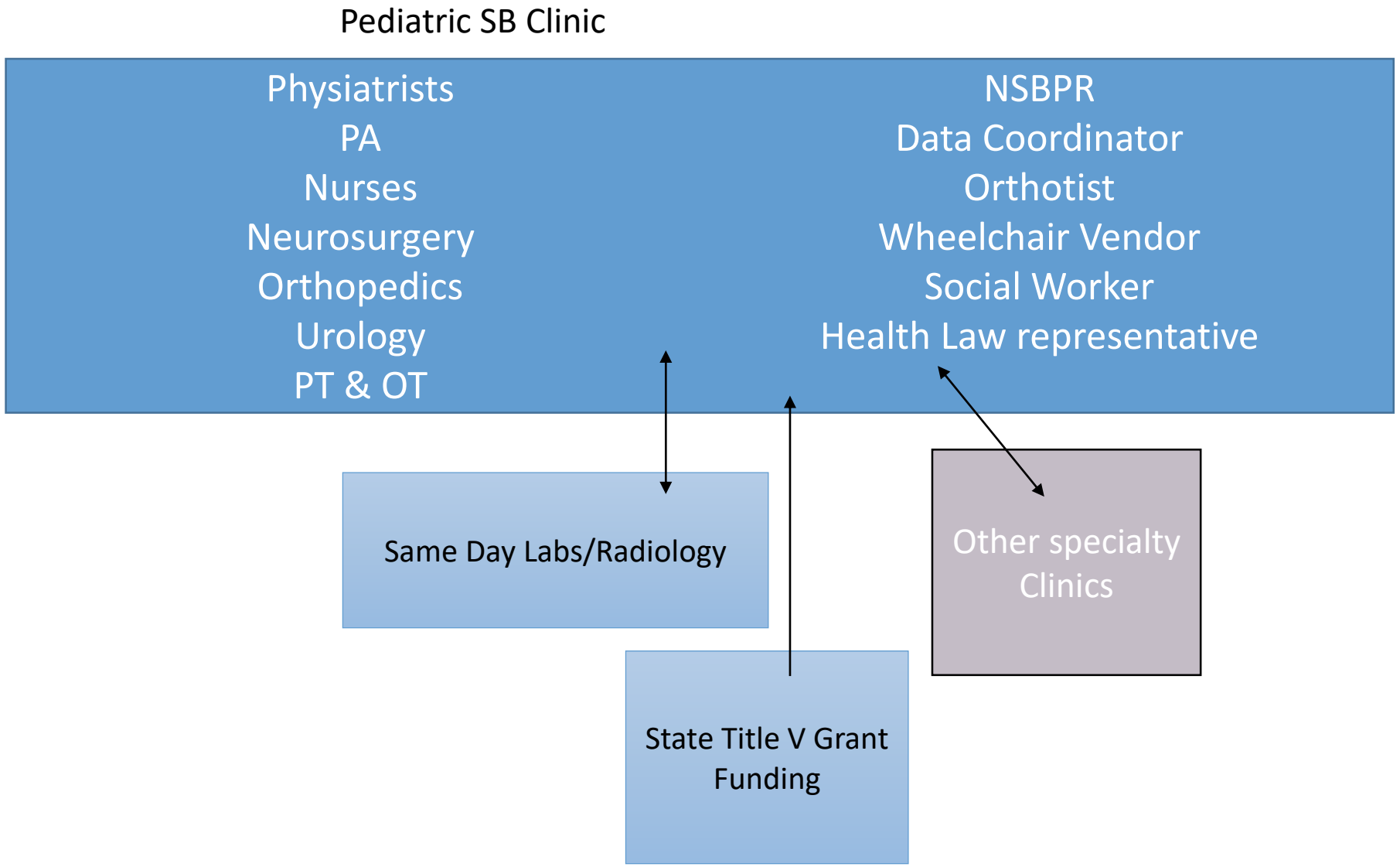


Hospital/EC visits during transition process (in progress)

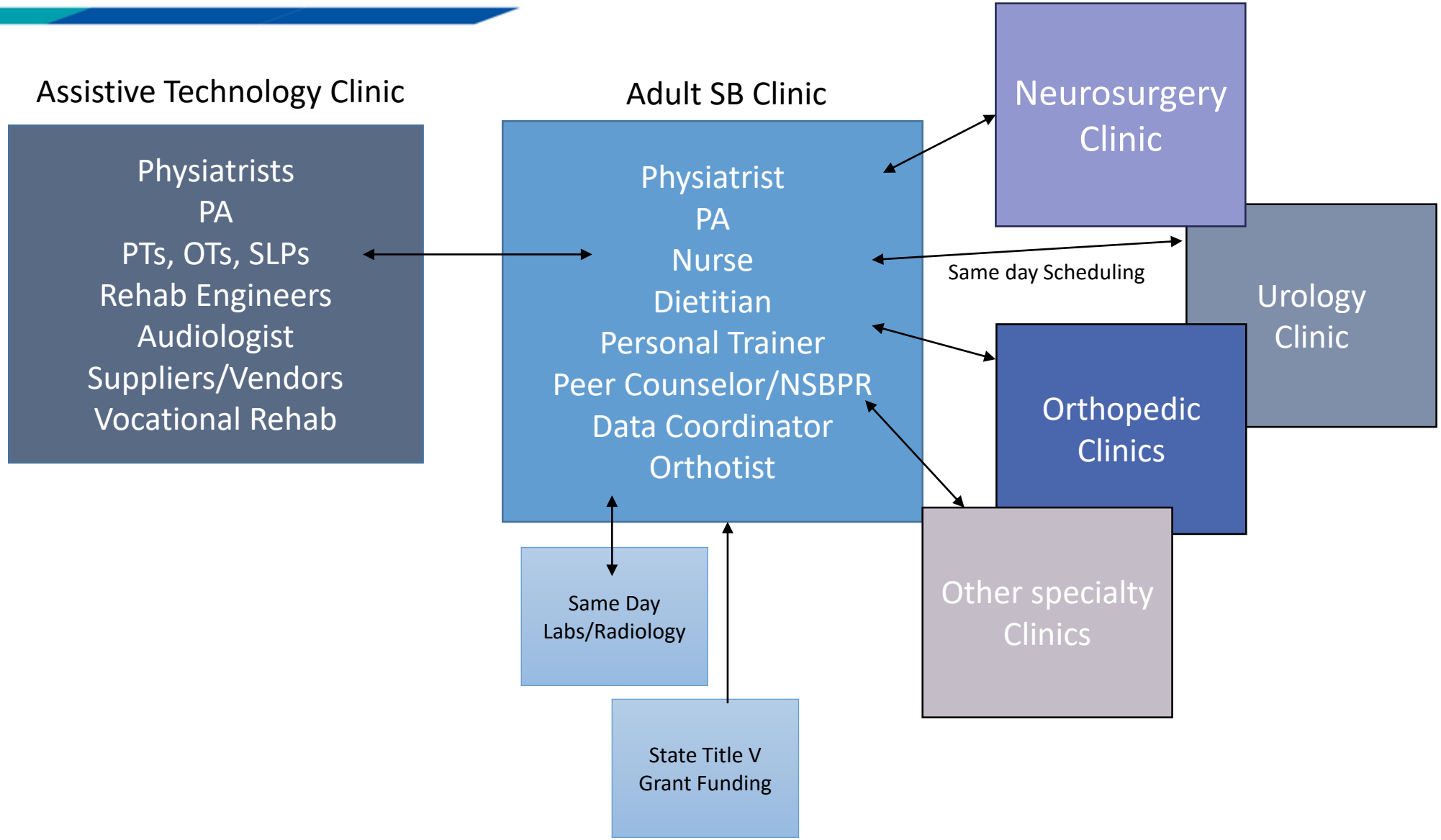
Barriers

- Adult subspecialty providers willing to accept Medicaid and knowledgeable about SB
- Variable patient follow-up rates in the transition program
- Changes in or loss of coverage from pediatrics to adulthood
  - Insurance coverage/changes –Urologic supplies/Orthotics
  - Not meeting qualifications for adult Medicaid
  - Limitations of home and community based services

University of Pittsburgh Pediatric Model



University of Pittsburgh Adult Model



University of Pittsburgh Model

- Components of program
  - Framework used:
    - “Got Transition”
  - Measures of success:
    - Percent of patients completing transition
    - Transition self-assessment
    - Transition surveys of patients and caregivers
  - Barriers encountered:
    - Age 26 hospital transition policy
    - Out of network patients at adult vs pediatric hospitals
    - 2 separate locations and 2 EMRs
    - Surgical specialists not available for adult outpatient clinic
    - Hospital-based clinic and copays

University of Pittsburgh Model

Why this program works in this particular setting

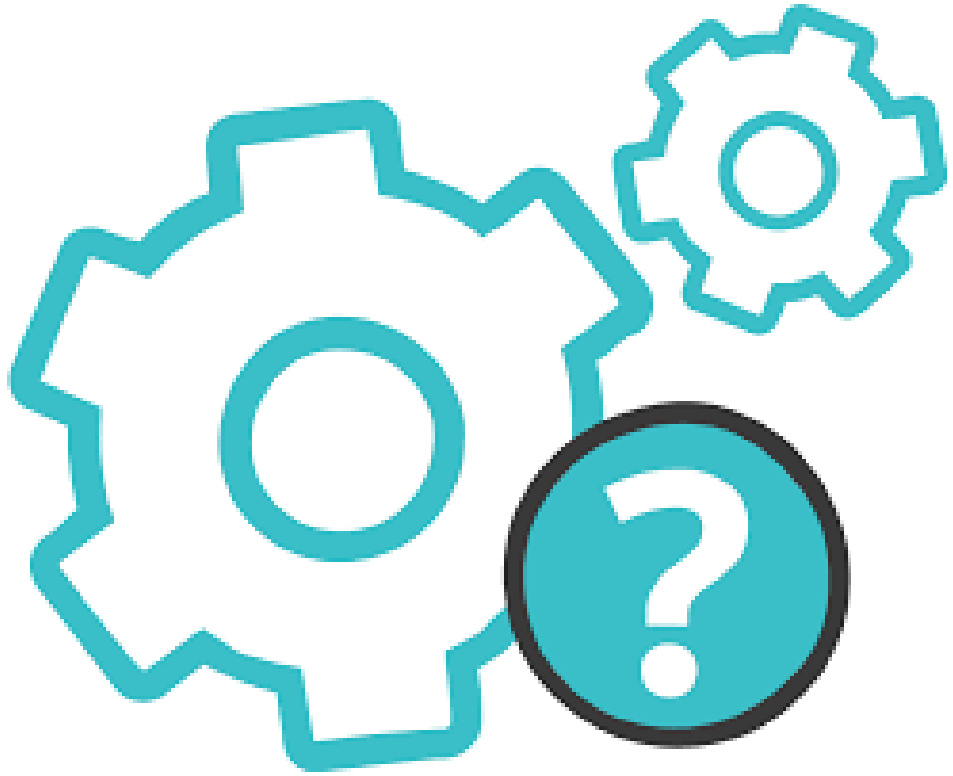
- Pediatric and Adult programs both within PM&R
- We use SBA Transition Summary form
- Title V funding through PA Dept. of Health
  - Patient Assistance Funds
  - Staffing for unique services
  - Employ people with SB
- Physician Assistant “bridges the gap”
- Adult Urology and PM&R in close proximity
  - Ability to do same day scheduling and testing
- Assistive Technology clinic
- Good communication with adult surgical specialists

pennsylvania
DEPARTMENT OF HEALTH

Open Discussion

How can SBA support individual clinics to develop transition programs?

- What do transition clinics want and need?
- How can SBA facilitate?



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